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ABSTRACT

This final report describes the process and steps the Kansas Services Project for Children and Youth with Dual Sensory Impairments Project (KSDSIP) has taken to provide services and technical assistance for infants, toddlers, children and youth with deaf-blindness. The 4-year federally funded project met federally-set priorities through identification of children and youth, location , and coordination of services for youth with dual sensory impairments. The project involved a pilot project on student portfolio development that documents longitudinally student accomplishments, needed adaptations, and accommodations, including transition to the next environment or postsecondary environments. Seven original goals provided the framework set for the project's activities: (1) identify children and youth who have dual sensory impairments; (2) provide training, consultation, and technical assistance to public and private agencies, institutions, and organizations on effective practices related to dual sensory impairments; (3) provide resources for families with children who have dual sensory impairments; (4) support the provision of effective practices for infants and preschoolers with dual sensory impairments; (5) provide transition services for youth with dual sensory impairments; (6) coordinate activities with appropriate agencies and organizations; and (7) disseminate information about resources and effective practices related to dual sensory impairments. Each goal is

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presented with the process and goal modification. Included in this final report is the context in which these goals were implemented along with problems encountered and the solutions. The implications for policy, practice, and research are explored. Research shows an average of 100-110 students from 33 districts or state schools have benefited from the comprehensive deaf blind service provided each fiscal year. (AA)

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Final Four Year Progress Report
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KANSAS SERVICES FOR CHILDREN AND YOUTH WITH DUAL SENSORY IMPAIRMENTS PROJECT

H025A50015

FOUR YEAR PERFORMANCE REPORT
OCTOBER 1, 1995-SEPTEMBER 30, 1999

Executive Summary

The purpose of the Kansas Services Project for Children and Youth with Dual Sensory Impairments Project (KSDSIP) was to meet the federal priorities by providing services; a) to infants, toddlers, children, and youth with deaf-blindness, and b) technical assistance to public and private agencies, institutions, and organizations. Kansas met these priorities through the identification of children and youth, and through the location and coordination of services for children and youth with deaf-blindness. Assistance was provided to agencies and organizations on effective practices related to the education of students with deaf-blindness. Specialized training for personnel working with children birth to years of age were provided and supported by the project. Resources and activities were provided to families of children and youth with deaf-blindness.

A pilot project on student portfolio development was executed to document longitudinally student accomplishments, needed adaptations, modifications, and accommodations, including transition to the next environment or postsecondary environments. Training sessions on portfolio development were conducted on a request basis. Approximately, five training sessions occurred within the state, as well as two national presentations. The *Student Portfolio* is widely used across the state of Kansas with at least a 1,000 audience dissemination statewide and 500 audience dissemination nationally.

Seven original goals provided the framework for the grant activities:

1. Identify children and youth who have dual sensory impairments.
2. Provide training, consultation, and technical assistance to public and private agencies, institutions, and organizations on effective practices related to dual sensory impairments.
3. Provide resources for families with children who have dual sensory impairments.
4. Support the provision of effective practices for infants and preschoolers with dual sensory impairments.
5. Provide transition services for youth with dual sensory impairments.
6. Coordinate activities with appropriate agencies and organizations.
7. Disseminate information about resources and effective practices related to dual sensory impairments.

The original proposal continued to meet the complex needs of the 99 students (currently approximately 130 students) identified with deaf-blindness in Kansas, as well as parents, families, and educational staff members. The project activities were provided through collaborative efforts of various agencies and administrative, organizational, and supportive services through the Kansas State Board of Education (currently the Kansas State Department of Education).

Project Description and How the Goals were Accomplished

It should be noted a new Project Director was hired November 1, 1995, during the project year 1995-1996. Many revisions occurred with project products, activities and goals during this time. Therefore, the following will contain information regarding summaries of explanations of the proposed and revised goals in the proposal, and modifications (including those suggested by the federal, peer review on-site evaluators and an external evaluator).

Goal 1: Identify children and youth who have dual sensory impairments.

Objectives and activities related to this goal included child find activities and assistance related to certification procedures. Since the fist year of the grant cycle, an additional 26 children have been certified (a 27% increase over the grant cycle). This increase was partially due to the production of project materials (available in Spanish, braille, and English) and the dissemination of these materials through meetings, conferences, and resource packets sent to newly identified children and their families. Additionally, a three year collaborative effort between Kansas School for the Blind (KSSB), Wichita State University, Washburn State University, Kansas Department of Health and Environment (KDHE), and KSDSIP have collaborated with product development, resource dissemination, and training on Usher Syndrome in conjunction with the state mandated vision screening training in Kansas. Eight training sessions were conducted a year with approximately 30 participants per session. Participants learned how to conduct vision and Usher screenings. Distance education also was offered as an alternative to attending the on-site training sessions. Satellite training was sponsored by Washburn State University Division of Community Nursing, using the vision and Usher screening training videotape with accompanying materials upon on district request. Approximately, 25 participants were trained in screening methodology using this media with a 4.3 overall mean satisfaction rating (on a five point scale). Knowledge skill acquisition (posttest) ranged from 88% to 100% with an 80% criteria for passing the screening session.

Certification guidelines were changed during the last four project years to provide a closer match with the census guidelines proposed by the NTAC project. For example a 25dB hearing loss (sensorineural or conductive) is currently considered as a hearing loss for certification, and both functional vision and hearing evaluations (along with medical records) are required. This increase in decibel levels paired with the required vision loss

listed in the certification guidelines qualified students as deaf-blind. To help ensure a smooth transition between student and adult service there was a provision where parents can indicate whether they would like the information shared with Helen Keller Regional Center Offices (HKNC). A written letter of permission to release records was required. Although there have not been many of these requests, the sharing of information has increased since 1995 (approximately 5% increase) which hopefully led to a seamless transition between schools and postschool environments.

The Kansas Deaf-Blind Fund for the last four years has been maintained at $110,000 funding level until the last year of the grant cycle. An average of 100-110 students from over 33 districts or state schools have received assistance for students who currently were certified as deaf-blind (July 1 to December 31 per fiscal year) in the areas of assistive technology, adaptive equipment, consultation, evaluation, or other. After January 1 per fiscal year, the fund was open to students with severe multiple disabilities and/or deaf-blindness on a first come, first serve basis until monies were encumbered or expended. The majority of requests were for assistive technology or adaptive equipment during the last four years. Guidelines were established for use of the fund during year one of the project. These were revised during year four after PL 105-17 was passed to reflect the use of assistive technology at home based on the IEP team's decision. Currently, the fund has been reduced to $108, 900 due to the Governor's mandated one percent budget cuts in human services and education (during fiscal year.1999).

Modifications to Goal 1: Although the number of vision screenings increased over the last four years, no hearing screenings were requested. Those individuals who passed certain levels of hearing screening tests (Levels I and II) through a supervised practicum conducted hearing screenings by certified school audiologists. Approximately, 10-20 hearing certifications occurred each year, with recertification required every three years. This certification training, combined with the new legislation of mandatory newborn hearing screening was conducted by Kansas State Department of Education (KSDE), KDHE, and Kansas State School for the Deaf (KSSD). Therefore, it was terminated as an activity of KSDSIP approved by the KS Deaf-Blind Advisory Council and KSDE.

The federal, peer on-site evaluation recommended continuing to translate project materials in other languages and communication systems (e.g. braille). This has been accomplished on a consistent basis, since the project has hired a consultant whose primary language is Spanish, second language is English, and third language is ASL (she is a consumer with Usher Syndrome II) and the agency purchased a braille printer and software, and TTYs for the Project Director and the Project Secretary. The Project Secretary was trained, along with two other office members on the translation of braille software program and the use of TTYs.

Goal 2: Provide training, consultation, and technical assistance to public and private agencies, institutions, and organizations on effective practices related to dual sensory impairments.

Objectives and activities related to this project included training for personnel who provide educational services to students who are deaf-blind and technical assistance to staff regarding effective practices related to students who are deaf-blind with associated activities. Beginning the summer of 1996, a cosponsored activity was conducted to educate personnel on inclusion, program modifications, and systems change related to the Kansas Quality Program Accreditation (QPA) requirements. This activity was cosponsored by the Supported Education in Kansas Project (SEIK), KSDE, KSDSIP, and the University of Kansas. Participants attended in teams consisting of general educators, special educators, and parents. Additionally, a mini-grant process was used to help support staff members who work with students who have dual sensory impairments in order to increase their knowledge base and education. Approximately, 10-20 mini-grants were awarded over the last three years of the project with approximately 55% full implementation of activities listed on the grantees' action plans. During the last grant year, 1998-1999 there was no requests for mini-grants.

During years two and three of the project, additional training activities included Hand in Hand training (Joan Houghton and Terry Rafalowski Welch), Contextual Assessment (Harvey Mar), Mental Health for Individuals with Usher Syndrome (Marlin Minkin), and the establishment of a field based consultant (FBC) training network (see modifications this section). All training activities were cosponsored by KSDE, SEIK, NTAC, KSDSIP, and/or KSSB. Two of the three training sessions were offered for graduate credit from the University of Kansas or CEUs for ancillary staff members. Two of three training sessions (contextual assessment-student centered teams, and Hand in Hand) required assignments and practicums from participants in which degrees of knowledge acquisition and implementation were measured. Approximately, 44% of recommendations were recorded full implementation from five teams and 33% of activities were recorded full implementation of 30 participants during the Hand and Hand training (27 participants did not attend the last training session).

Technical assistance provision was provided by the Project Director and outside consultants during years one to two of the project. Approximately 66% of activities recorded full implementation by outside consultants. Approximately, 60% of activities recorded full implementation provided by the Project Director. Technical assistance usually consisted on on-site consultations and mini-inservice training. Technical assistance was always followed by follow-along activities of the receiver's choice, such as videotape review, telephone contact, or a second on-site visit. The majority of requests were made by service providers during years one to three of the project. Only four requests were made by parents. Average technical assistance provided by phone contacts included 30 hours per year for both parents and service providers (not including contacts made by the Project Secretary and Census Coordinator). Mail logs revealed approximately 700-900 pieces disseminated that are directly related to project activities, such as services booklets, certification guidelines, newsletters, FAQ regarding the deaf-blind fund, and/or directory cards.

Modifications to Goal 2: The field based consultant network was established to provide a cadre of teachers in the field that sustained support to service providers, and provided various levels of technical assistance to students with severe disabilities and deaf-blindness. During years three and four of the project, 11 FBCs were selected to provide technical assistance coordinated through an FBC Coordinator, and managed by members from KSDE, KSDSIP, and the University of Kansas. Five days of each FBC contract was bought out from their respective districts. The districts provided two days of professional development leave (e.g., fall and spring seminars). Content of the seminars was based on the needs identified by FBC's and the people with whom they provided consultation. One half day of the training was based on FBC processes and procedures with the remaining day opened to a larger audience. It is estimated at least 113 individuals were affected by FBC consultations during years one and two of the project. The number of students with deaf-blindness who have received services by an FBC is approximately 13-15 with content areas related to transition, communication, and program modifications. Approximately 66% were recorded full implementation of activities and 33% reporting no progress or follow-up data were not collected.

The change in technical assistance delivery was partially due to the federal peer review on-site evaluation that a recommended utilizing local resources to provide technical assistance, and to continue accessing technical assistance and training resources through NTAC (see transition goal). The NTAC representative was hired to conduct one technical assistance activity; however, was discouraged to conduct more activities in the state due to a conflict of interest with her project.

A technical assistance process and procedures was initiated and piloted in state, with assistance provided by Kat Stremel (an NTAC sponsored activity). Currently, this process is being revised to be more manageable and obtain data that are relevant to child, family, and systems impact as required by the federal priorities of the new grant award.

The Kansas Deaf-Blind Advisory Council was inadvertently left out of grant activities during the first year of the project. Attempts were made to redesign an advisory board that had greater involvement in project activities during year two of the project. The result ended in the initiation of the Kansas Deaf-Blind Task Force. Task force members chose to serve as a separate, private entity rather than be a part of KSDSIP.

Based on the recommendations of the federal peer on-site evaluation, an official Kansas Deaf-Blind Advisory Council was developed consisting of representation from business, parents and families, educators, administrators, vocational rehabilitation, and university personnel. The Advisory Council met two times a year for years three and four of the project. During year four, the council revisited their roles, participation, and involvement in project activities. Overall, satisfaction of Kansas Deaf-Blind Advisory Council Meetings was 4.8 (on a five-point scale). (This also was a recommendation from the Summative Evaluation Report, 1997-1998.)

Goal 3: Provide resources for families of children with dual sensory impairments.

Objectives and activities under this objective included providing support for training related to the education and transition needs of families of students with dual sensory impairments. This was primarily delivered through family scholarships awarded to families for the education and training of their children (e.g., workshops, etc.). An average of 3.5 requests per project year resulted in family scholarships for attending conferences, workshops, and meetings both in and out of state. Additionally, an average of four requests per year was made by parents during years one to three of the project. Most of the requests centered on connecting with resources and one request resulted in on-site technical assistance by the Project Director.

Modifications to Goal 3: Based on the federal peer on-site evaluation, a parent consultant was contracted to conduct one to one telephone needs assessment with each parent on the census during year four of the project. This resulted in 10 requests for technical assistance that were provided by the either Project Director or an FBC. Additionally, a parent newsletter was implemented (published two times per year), *Anything and Everything*, which is written by parents and has an all parent editorial review board. Parents also decided they wanted a parent directory of other parents and resource personnel with whom they could connect that was available to parents only. A collaborative activity between NTAC, D-B Link, and NTAC produced the directory. It is published in both English and Spanish. Additionally, an outcome of the parent needs assessment survey resulted in a document was a report on the state of the state for the families of students who are deaf-blind. This was disseminated nationally and to the Kansas Board of Education during their 1998 board meeting.

Goal 4: Provide support for the provision of effective practices for infants and preschoolers with dual sensory impairments.

Objectives and activities under this goal included support of the INSTIE preschool curricular model in Kansas and provide assistance to programs serving young children with dual sensory impairments. The INSTITE model was not implemented during the four years of the project, since the trainers never received instruction in implementation of the full model, nor were there dollars to support the parent trainers. Technical assistance for infants, toddlers, and preschoolers was not requested during year one of the project. However, during years two through four of the project, an average of seven technical assistance requests were made for infants, toddlers, and preschoolers each year. These requests were provided by FBCs, private consultants, or the Project Director.

Modifications to Goal 4: Since there is no preservice program in vision impairments or blindness in Kansas, it was determined to adopt and implement the VIISA training program based out of the University of Utah (SKI-HI). Fourteen trainers received training from the VIISA national trainer. Since year two to four of the project,

approximately 45 participants have been trained in VIISA for infants and toddlers and 45 participants have been trained in VIISA for preschoolers. VIISA trainers conducted the training sessions, assignments, and practicums. Graded graduate credit from the University of Kansas was provided. Participants were required to complete all assignments and attend all training sessions regardless if they are taking the class for credit or not in order to receive VIISA certification. Supplemental training sessions in the summer for VIISA trainers was provided to update skills and provided additional information on adult learning strategies. This was based on recommendations from the federal peer on-site evaluation. An overall mean of satisfaction for all of the training session is 4.4 (on a five point scale), and assignments are completed at an average 90% implementation level.

Goal 5: Provide transition services to children and youth with dual sensory impairments.

Objectives and activities included under this goal included providing information to LEA staff and families about coordinated life planning and technical assistance and information to LEA and adult service agency staff about transition. During the first year of the project, the student portfolio document was piloted and implemented in model sites to determine the effectiveness, usability, and validity of the product. Only one of three pilot sites submitted data. Results included ease of use, portability, and whether the system was a meaningful and functional way to promote transition to the next environment. One inservice training was provided in collaboration with HKNC Representative on transition from a residential facility to the student's home state. The Regional Representative has continued to provide technical assistance for the transition of the student to his home state. Finally, the project co-sponsored the attendance of one student at the first AADB National Teen Conference in Tulsa, Oklahoma.

Modifications to Goal 5: During years two through four of the project, Transition Connections was developed. This model was adopted and adapted from the HKNC-TAC Model on transition for young adults with deaf-blindness to postschool environments. Five student centered teams were accepted to participate on an application basis. Teams received two training sessions per year that were action oriented with team derived goals and objectives. Individual student-centered team meetings were conducted between training session to assist in the transition issues, problem solve, and make decisions on the direction teams were heading in the implementation of transition services. An average of 70% full implementation was reported for all teams during their meetings and workshops.

FBCs provided technical assistance to an average of three transition related technical assistance requests per year for years two through four of the project. Additionally, the Project Director was directly involved in two ongoing transition activities for students on the census. Some of the FBCs are Transition Connections Team members. Again, approximately 66% of the technical assistance requests provided relating to transition have resulted in full implementation.

Student portfolios were terminated after year two of the project since the document was produced and disseminated, training sessions were conducted, and pilot teams served as models for other school districts and cooperatives. However, based upon request, training on student portfolio development was offered during years three and four of the project. The *Student Portfolio* was disseminated and purchased upon request (approximately 1, 500 were disseminated and over 600 were sold).

Goal 6: Coordinate activities with appropriate agencies and organizations.

Objectives and activities under this goal included coordination of activities with the Kansas State Board of Education Special Education Outcomes Team (now Kansas State Department of Education, Student Support Services Division) and activities with other relevant projects, agencies, and organizations. Various and numerous activities have been preformed by the Project Director in direct relation to KSDE activities, Student Support Services Division throughout the four years of the project. Some of these included participation on past existing function and issue teams (e.g., Assisstive technology, Leadership Team, OT and PT Guidelines, Alternate Assessment Team, Adaptive PE Guidelines, Staff Development Team, IEP Function Team, and transitioning students during the closing of Winfield State Hospital during 1996).

Coordination with other projects and agencies are various and numerous during the four years of the project. Project collaboration included SEIK, Wichita State University, Washburn University, Association of Central Colleges in Kansas (ACCK), the University of Kansas, Kansas Statewide Transition Systems Change Grant, School to Careers Grant, HKNC, KSSB, KDHE, Helen Keller Affiliates, Families Together, Kansas Deaf-Blind Task Force, NTAC, KSSD, and a collaborative personnel preparation effort with the University of Kansas for graduate work in deaf-blind education.

Goal 7: Disseminate information about resources and effective practices related to dual sensory impairments.

Objectives and activities under this goal included disseminating information about resources to service providers and families. All Special education Directors (approximately 171) received project information packets each year of the project. Additionally, project information and resources for purchasing are displayed at every KASEA regional meeting, state conferences, KSDE sponsored activities, and state and national conferences during all four years of the project. In addition, over 150 new resources (making approximately 600 entries) were purchased for the Kansas Deaf-Blind Loan Library, which was moved to Kansas Instructional Resource Center (KIRC) during year three of the project. All resources were located online and were available for loan to anyone in the United States. Approximately, 150 consumers used the library each year including parents, undergraduate and graduate students, teachers, paraprofessionals, and service providers. When possible, resource items were purchased in Spanish and English.

There was an average of four presentations per year to undergraduate and graduate level classes on vision, orientation and mobility, transition, portfolio development, and characteristics of deaf-blindness. Overall, mean average of the presentations was 4.7 (on a five point scale). Additionally, three project manuals were developed and disseminated, *Student Portfolio, Usher Screening Manual,* and *Families of Children with Deaf-Blindness: A Report on the State of the State*. The costs accrued from the first two publications are put in a conversion to purchase resource materials for the Kansas Deaf-Blind Loan Library. The last publication is free. All publications are available in braille and Spanish.

Modifications to Goal 7: Based on the recommendations of the federal peer on-site evaluation, the Kansas Deaf-Blind Loan Library was moved from Southeast Kansas Service Center to the KIRC at KSSB in Kansas City, Kansas. A current directory of resources was published and disseminated to all special education directors, service providers, and parents (approximately 3,000 audience mailing). This move also was recommended in the Summative Evaluation Report, 1997-1998.

Context

The implementation of Goals 2000 and the Kansas Quality Performance Accreditation that were mandated strongly influenced the needs for systems to provide a unified system of education for all school age students regardless of where they received educational services. This served as a basis for determining needs of students who were deaf-blind and severe disabilities. In order to meet the mandates of fully including students with disabilities in integrated activities and settings, massive staff development needs were identified to train and retrain general and special educators, related service providers, families, and administrators.

A major change in state and federal mandates since the time of the grant's inception were mandated services for students birth to two years of age and students thirteen through 21 years of age. Since the time the grant was awarded, Kansas now mandates services through an interagency agreement with Part C for children birth to two years of age, and transition planning for students beginning at age 14; therefore, all students who receive special education services are covered under state and federal educational legislative mandates.

Needs assessment data were collected from a variety of stakeholder groups to determine the goals, objectives, and activities for the grant. These included both formal and informal methods of needs data collected from the Kansas Deaf-Blind Advisory Council, Parent Surveys, Summer Institute Surveys, Statewide Workshop Surveys. The top five priority needs identified through these various entities included; 1) training (e.g., infants and toddlers who were deaf-blind, inclusion strategies, and transition), 2) developing a pool of technical assistance providers, 3) assistive technology, 4) collaborative teams, and 5) classroom modifications and adaptations.

These identified needs combined with the changes in federal and state legislation served as a basis for grant development. Goals, objectives, and activities directly related to the needs and mandates, as well as the requirements in the request for funding proposal. However, needs assessments were ongoing throughout the four-year grant cycle that included both content and process needs of parents, families, educators, and services providers.

Needs assessment surveys along with a technical assistance request forms were sent to approximately 1500 to 3000 administrators, services providers, and ancillary staff members who may have touched the lives of a child with deaf-blindness. This survey was sent every year of the project with approximately a 17.5% to 22% return rate. Additionally, a parent needs assessment survey and technical assistance request forms was sent during years one and two of the project (approximately 99-105) with 14 needs assessment surveys returned and four technical assistance requests submitted. Based on a recommendation from the federal peer on-site evaluation, needs assessment information was conducted by the parent consultant through one to one telephone contacts during years three and four of the project. This activity increased the amount of needs identified by parents and parent technical assistance requests tripled.

Needs assessment data (from service providers and administrators) for the four years of the project revealed the following needs in regards to content and process. Changes made in the grant activities were based on the needs identified. The top priority needs for content and process included: 1) content-transition, communication, greater amount of technical assistance delivery, Usher Screening system, functional curriculum, complex health care needs, and vision training for infants, toddlers, and preschoolers; and 2) process-onsite consultation after initial visit or inservice training and follow-up phone contacts. Parent needs assessment data revealed priority needs of 1) assistive technology training, 2) resource packets on services provided to students and individuals on deaf-blindness, 3) linkages to state and national resources, 4) ongoing site assistance for overall program evaluation, 5) transition and 6) orientation and mobility. Additionally, the above needs paralleled those identified by other stakeholder entities, including the Kansas Deaf-Blind Advisory Council, Part C, the Kansas Deaf-Blind Task Force, and the NTAC Stakeholders Meeting.

Each of the above needs have been addressed through a variety of collaborative activities due to the limited fiscal resources of the grant paired with an increase in the student population. For example, resource packets have been developed, a Kansas Directory for Parents was developed, Transition Connections Teams were developed, an FBC network to build local capacity for the delivery of technical assistance was developed, and the adoption of the VIISA program. These changes occurred to meet the needs of constituents.

Describe Problems Encountered and How They were Solved

During the first year of the project (after the change in Project Directors), the Deaf-Blind Census had not been maintained according to the guidelines that were established. The census data were reviewed and corrections were made regarding the identification of students. This lead to the underidentification of students during year two of the project (84 students); however, the census increased during years three and four (125 students at the end of year four). This was partially due to notification of directors' regarding the student's certification or recertification status and the extensive marketing efforts by disseminating project materials at various meetings, conferences, and workshops.

During the first year of the project (after the change in Project Directors), the Kansas Deaf-Blind Fund never had any official established guidelines on to the use of the fund, how much could be requested per student, or the timelines on when the fund could be accessed. An official document that lists state and federal legislation, how to apply, the amount available per student, encumbrances, and expenditures were clearly described in a question and answer format. This has allowed expeditiously tracking the encumbrances and expenditures of the fund and lessened the ambiguity of how many students received funding or which students qualified for funding. Additionally, the fund was transferred to a computerized accounting system.

During the first year of the project (after the change in Project Directors), there was no systematic procedure or process for delivery of technical assistance. Therefore, implementation data, child change data, and knowledge acquisition data were missing from the files. An NTAC Agreement provided a model for better tracking the effects of technical assistance delivery. This model was piloted during the remaining years of the grant cycle. Although various types of data were recorded in regards to technical assistance areas, data could not be aggregated to determine impact on family, child, educator and systems change. However, this is being resolved during the grant cycle 1999-2003 with assistance of the evaluation specialist. Additionally through assistance of the FBCs, more students with deaf-blindness and their families were provided on an ongoing basis. Finally, another factor on the increase of technical assistance from families was generated through the telephone contacts from the parent consultant.

During the fist year of the project (after the change in Project Directors), a revitalization of the Kansas Deaf-Blind Advisory Council was pursued with the intent of making the Advisory Council more of an action oriented task force model. This attempt failed; however, the Kansas Deaf-Blind Task Force continues to exist and has chosen to serve as their own entity without KSDE support. The Kansas Deaf-Blind Advisory Council continued to serve as a knowledge gathering capacity. During this grant cycle 1999-2003, the function of the Kansas Deaf-Blind Advisory Council is being revisited and reorganized to meet the federal priorities in the grant award.

After the implementation, training, and dissemination of the portfolio ended during year one and half way through year two of the project, Transition Connections Teams were implemented. This is the most parental involvement that has occurred in any activity sponsored by KSDSIP. The same applied to the Contextual Assessment Training; all parents attended both training sessions with their teams. It appeared parents were more interested in attending training when it was specific to their child and with team members, than gathering in large groups or regional family meetings. The parent consultant also indicated this through the parent needs assessment data obtained.

The INSITE training that was to provide parent mentors after reaching specific competency criteria conducted during the first year of the project failed since the INSTIE Model was not followed. VIISA training was being offered in its place. After speaking with a VIISA advisory council members, the VIISA program was implemented since there is no personnel preparation program in the state and there is a demand for teachers of the visually impaired. This has proven successful as stated in the above section, Project Description and How the Goals were Accomplished.

The location and operation of the Kansas Deaf-Blind Loan Library (PIN) was too far from the office and ineffective in the delivery of loaned material. After several attempts to correct the loan process, the library was moved to KIRC at KSSB. The library resources were bar coded and available for checkout on the Internet. The contact for the library was an ex-vision teacher and librarian. The location was only one and one-half hours away from the KSDSIP office.

The amount of collaborative and coordinated activities of the project with KSDE activities increased the responsibilities of the Project Director. Even though collaboration and coordination of activities among various projects and KSDE were important to the activities of the project, it was noted by an external evaluator and the federal peer on-site evaluation that too many collaborative projects can spread thin resources too thin resulting in compromising the quality of service delivery. Both evaluations suggested re-examining activities and determining which had the most impact.

Implications for Policy, Practice, and Research

The National Association of Special Education Directors'(NASDE) in 1998 published a document relating to the needs of students who are deaf-blind. Contained within document, were recommendations toward the status, best practices, teacher competencies, and postschool outcomes for students who are deaf-blind and their families. These recommendations were representative of values, beliefs, and needs education and postsecondary programs of students with deaf-blindness on a national basis, as well as Kansas. KSDSIP wholeheartedly supported NASDE's (1998) recommendations. The recommendations from NASDE (1998) were referenced in the current grant proposal 1999-2003. Due to the comprehensive nature of these

recommendations, no further recommendations were made regarding policy, practice, and research.

Families of Children Who Are Deaf-Blind in Kansas

A Report on the State of the State

EC 307610

Families of Children Who Are Deaf-Blind in Kansas:

A Report on the State of the State

By Cynthia Thomas
Edited by Jacqueline Schafer

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Why was this report prepared?

Today, the family is generally considered the primary support system for children with disabilities. For that support system to be truly successful, however, the needs of those families must be taken into consideration by the professionals who serve them. Unfortunately, determining these needs is not always easy.

In 1997, this was the dilemma facing the Kansas Dual Sensory Impairments Project. In search of information about how to better meet the needs of children who were deaf-blind, project staff developed a questionnaire and sent it to all families on the Kansas Deaf-Blind Census. When only a few responses were returned, project staff decided to obtain the information by actually calling and interviewing the 90 families who comprised the census.

Each phone interview typically lasted an hour. Approximately 60 interviews were conducted. Although mothers were the primary respondents, a few fathers and extended family members also responded.

Since establishing rapport was crucial to the success of the interviews, all surveys were conducted by a parent of a child who was deaf-blind. Having a fellow parent conduct the interview not only added to the comfort level of participants, but provided emotional support for many families. Some parents had never before spoken to the parent of a child who was deaf-blind. A few had never spoken to the parent of a child with *any* type of disability. Thus, being able to simply talk to another parent was a wonderful benefit for many of the parents interviewed. And, knowing that someone was taking the time to ask about their needs relieved many families' sense of isolation.

The current situation of families in Kansas

Children on the census have different degrees and combinations of hearing and vision loss. As a result, their abilities differ widely. Some children have absolutely no means of communication, while others speak quite well. Some read print; some braille. Some use American Sign Language (ASL), while others use home signs and behaviors to communicate.

Many of the children on the census have disabilities in addition to deaf-blindness. Some children have no medical problems, while others are in fragile health. Some are dying. Because doctors cannot say how a disease will progress when no one has seen it before, several families live with the terrible burden of an uncertain prognosis for their child.

Although most of the children live with their nuclear families, some live with extended families, a few with foster parents, and a few away at school. Some are a welcomed part of their communities; others are not.

Family and community resources

While a wide range of incomes and financial resources exist, most families face a financial burden because of their child's condition. Many times this burden is caused by the purchase of equipment for their child. Considering that an electric wheelchair can cost $15,000 and a computer with peripherals $5,000, this is easily believable. Repair and upkeep of equipment–costs seldom reimbursed by insurance or Medicaid—can also be financially draining. Replacing something as common as a wheelchair seat cover can set a family back $65.

The emotional and support resources available to families vary across the state. Some families receive help with care-giving responsibilities from extended family members and friends. A few have a network of friends, fellow parents, and professionals to help them when a challenge arises, but they are in the distinct minority. Other families receive attendant care or nursing services from outside sources. Many families struggle with the challenge of raising a child who is deaf-blind by themselves.

Knowledge of organizations that could provide help and support is severely lacking among the parents on the census. Most parents have never heard of (nor received help from) the National Family Association of Deaf-Blind, the Kansas Dual Sensory Impairments Project, the Kansas Deaf-Blind Task Force, or the Kansas Deaf-Blind Loan Library.

By and large, local churches or service groups like the Kiwanis and Lions clubs seem to be the primary sources that families turn to for assistance. Generally speaking, the support provided by schools is either limited or non-existent. From whatever source help is received, however, it is generally a one-time occurrence (e.g., to purchase a piece of equipment). There appears to be little on-going help on which families can rely.

Despite such limited support, many families draw strength from their faith, from their belief in their child's worth, and from their deep love for their child.

What parents want & need for themselves

Three major parent needs surfaced in this survey: access to practical information about deaf-blind issues, the ability to talk to parents who have children with similar health needs, and better trained personnel to work with their children.

1. Access to information

When parents were asked what would be the best way to obtain information about deaf-blind issues, their overwhelming response was a newsletter.[1] Frustrated with juggling the demands of work and home with the special needs of their child, parents expressed a desire for information that is quick to digest, easy to understand, and portable. Specifically, parents said that they are looking for information about how to help their children communicate, become valued members of their schools and communities, and eventually, to live and work independently. Parents with children nearing the end of high school expressed a desire for information on post-secondary education, training programs and organizations that teach daily living and vocational skills, and job opportunities.

As a corollary to this desire for information, parents expressed strong opposition to obtaining information through workshops or conferences.[2] Even if workshops were held at a near-by location and child care was provided, parents said that they had too many other responsibilities to spend time in a workshop.

2. The ability to talk with other parents

Parents also expressed a great desire to talk to parents who have children with similar health needs or abilities. The overwhelming means by which they want to conduct these conversations is by telephone—not a meeting. As a corollary to this desire, many parents expressed interest in a parent-to-parent network for families of children who are deaf-blind.

3. Better trained support staff

Finally, parents want the people involved in their child's education and care to be better trained. To the child with special health care needs, under trained staff poses a potential hazard. Training staff to accurately identify seizure activity and to know what to do when a child is having a seizure is an important need.

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1 This option was selected from the following choices: newsletters, local newspapers, tape cassettes, videotapes, e-mail, web sites, and conferences or regional meetings.

2 For parents familiar with Family Enrichment Weekends—an educational retreat organized and sponsored by Families Together—this opposition to attending workshops was also true. Parents who had previously attended these events said that they no longer attended because activities were geared more toward families whose children had different needs. Concerns about volunteer attendants being able to understand and communicate with children who were deaf-blind also contributed to their decision not to attend.

In particular, parents would like support staff to receive training on building peer friendships, inclusion, team collaboration, communication, and behavior management. Of particular concern to parents of children with health issues is that paraeducators and caregivers know how to maintain the child's health and well being. In addition, parents said that back-up or substitute staff need to be trained. When a paraeducator is ill, students are sometimes forced to stay home from school because no one else knows how to care for the children.

Other concerns about staff skills include:

- for children who use sign language, having school staff be able to sign at the child's level of competency (and with the same type of sign language);
- for children who use ventilators, having more health care providers trained in the use of ventilators;
- for children using electric wheelchairs, having more Orientation and Mobility instructors experienced in working with powered mobility, and
- for adolescents transitioning to the world of work, having well-trained job coaches.

"Frustrated with juggling the demands of work and home with the special needs of their child, parents expressed a desire for information that is quick to digest, easy to understand, and portable."

What parents want for their children

During the survey, parents also expressed three major desires for their children: to learn a functional communication system, to have access to more technology, and to have access to more meaningful employment opportunities.

1. To learn how to communicate

Parents realize that communication, whatever the style or level of ability, is essential to their child's quality of life. Many parents innately perceive that what is often construed as bad behavior on the part of their child is simply the child's attempt to communicate when no other means are available. Parents *want* to find more socially appropriate ways for their child to communicate. In addition, they see the ability to communicate as an important yet often overlooked safety issue. Children need to be able to express whether someone has threatened or hurt them, or even if someone has made them feel uncomfortable.

2. To have access to more technology

In many cases, children need technology and adaptive equipment in order to communicate, learn, access learning, do a job, or compete academically with non-disabled peers. Having qualified people who understand the diverse needs of children who are deaf-blind and who have the expertise to select technology and equipment to meet those needs is essential. Just as important is having teachers who know how to use the technology or equipment once it is available.

Parents want their children to use technology and to have greater access to it—both at school *and* at home. Keeping and using technology only at school does not prepare the student for its use at home or in the community. Parents often cannot afford duplicate pieces of equipment or technology for use at home. Thus, they would either like their children to be able to transport the technology between home and school, or to have a no-interest loan program that would allow them to buy the necessary equipment. And, they want the equipment and technology that students use in school to follow them into the real world.

3. To have access to more meaningful job opportunities

Parents wonder what their children will do once they graduate from school. Will there be jobs for them, or will they spend their days in isolation? And what will become of their children once they die? Who will take care of them? Thus, the third desire parents have for their children is that they acquire the skills they need to function as an adult, and that more emphasis be placed on the development of meaningful jobs for students who are deaf-blind.

For the parents of younger children, planning for their child's adulthood is a difficult concept to consider. Many are so caught up in the struggle of the moment that subjects like "future living arrangements" and "employment" are as remote as the moon. Not many parents realize they need to seek guardianship of their child when the child becomes 18. And, many do not know that boys still need to register for the draft even if they have a disability.

What we can do to help

Although the situation may appear grim, we can do a lot to make it better. Some families are doing well and their children are receiving the services they need. This seems to happen more with preschool and younger children, so perhaps as children move into elementary school, much of the ground work will be laid for a more productive school experience.

Usually, the families that get services do so because they network and negotiate. Unfortunately, not all parents have the skills of a lawyer, activist, negotiator, and political scientist. Kids should be able to get the services they need even when their mother isn't Sandra Day O'Connor. The burden should not rest on the parents. Parents and professionals need to work together to help every child in Kansas get the education they deserve.

Among specific ways that parents and professionals could work together include:

- establishing a parent/family interest group to provide on-going guidance about the types of services needed in the state;
- exploring the use of the Internet as a means of accessing resources not only in the state but across the nation;
- exploring greater collaboration with existing agencies for parents and families, and
- exploring the establishment of a website as a means of connecting parents with one another.

Where do we go from here?

In direct response to the needs survey discussed in this report, three positive changes have already occurred.

First, a telephone directory with names of parents included by consent has been prepared and disseminated through the coordinated efforts of multiple agencies.

Second, in an effort to provide parents across the state with access to practical information, a parent newsletter has been established. The content of this newsletter is conceived, written, and reviewed by parents of children who are deaf-blind. The newsletter is published twice a year in both English and Spanish.

Third, several transition teams have been established to facilitate the transition of students who are deaf-blind into meaningful employment, independent living, and recreation opportunities within their home communities. The driving force behind the teams' activities are the individual preferences and needs of the student. For example, one student has been offered full-time employment (with benefits) upon graduation from high school. Another student is returning to her home community to attend the school of her choice. And another student has increased his social activities through involvement with the local YMCA, where he has developed many natural and sincere friendships.

Even though these changes may appear small, they have greatly improved the lives of children and families in Kansas, and have become launching points for further connections.

Finally, the most important thing we can do is to believe in the worth of children who are deaf-blind. We must continue to teach educators, administrators, doctors, nurses, social workers, bus drivers, neighbors, and politicians that these kids matter and their education matters. The one real note of hope, heard over and over as parents spoke of their children, is the deep love and commitment these families feel toward their children. It is their strength. Together, that love is our hope—for the future of children in Kansas who are deaf-blind.

Familias de Niños

Que Son Sordos y Ciegos en Kansas:

Un Informe del Estado en el Estado

EC 307610

Familias de Niños Que Son Sordos y Ciegos en Kansas:

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Servicios en Kansas para Niños y Jóvenes en El Proyecto de Doble Impedimiento Sensorial # H025A50015, y Educación Soportada por el Proyecto de Kansas (SEIK), # H086J20012-96, son respaldadas por la Oficina de Programas Especiales de Educación, El Departamento de Educación de E.U.A. La Información obtenida dentro de esta publicación no refleja necesariamente los puntos de vista de El Departamento de Educación de E.U.A.

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¿Por qué se preparó este informe?

Actualmente, la familia generalmente se considera como el sistema primario de apoyo para niños con incapacidades. Para que ese sistema de apoyo sea verdaderamente exitoso, sin embargo, las necesidades de esas familias deben ser tomadas en consideración por los profesionales que les sirven. Desafortunadamente, determinar esas necesidades no siempre es fácil.

En 1997, este era el dilema que confrentó El Proyecto de Doble Impedimiento Sensorial de Kansas. En busca de información sobre como encontrar mejor las necesidades de niños quien eran sordos y ciegos, el personal de proyecto desarrolló un cuestionario y envió a todas las familias del Censo Sordo y Ciego de Kansas. Cuando solo unas pocas respuestas se devolvieron, el personal del proyecto decidió obtener la información directamente l'amando y entrevistando las 90 familias que comprendió el censo.

Cada entrevista por teléfono típicamente duró una hora. Aproximadamente 60 entrevistas se condujeron. Aunque las madres fueron las primeras en responder, algunos padres y parientes cercanos también respondieron.

Como establecer una buena relación de communicación era crucial al éxito de las entrevistas, todas las encuestas fueron conducidas por el padre de niño quien era sordo y ciego. Al tener a un padre conducir la entrevista no solamente aumentó el nivel de comodidad de participantes, pero dió apoyo emocional a muchas familias. Algunos padres nunca antes habían hablado con otro padre de un niño quien era sordo y ciego. Algunos otros nunca habían hablado con el padre de un niño con cualquier tipo de incapacidad. Así, que simplemente hablando con otro padre fue un beneficio maravilloso para muchos de los padres entrevistados. Y, saber que alguien tomó tiempo para preguntar sobre sus necesidades ayudó a muchas familias a salir de su aislamiento.

La situación actual de familias en Kansas

Los niños en el censo tienen combinaciones y grados diferentes de pérdida de visión y audiencia. Como resultado, sus capacidades difieren ampliamente. Algunos niños no tienen absolutamente ninguna manera de comunicación, mientras otros hablan bastante bien. Algunos leen imprenta; otros braille. Algunos otros usan American Sign Language (ASL), mientras otros usan sus propios signos y señales para comunicarse.

Muchos de los niños incluidos en el censo tienen incapacidades además de ser sordos y ciegos. Algunos niños no tienen problemas médicos, mientras otros su salud es delicada. Algúnos estan muriendo. Porque los doctores no pueden decir como una enfermedad progresará cuando ninguno lo ha visto antes, varias familias viven con la carga terrible de un pronóstico incierto para su niño.

Aunque la mayoría de los niños viven con su familia cercana, otros viven con parientes lejanos, otros pocos con padres adoptivos, y otros viven en la escuela. Algunos son aceptados en sus comunidades; pero otros no.

Recursos de familia y comunitarios

Mientras una gama amplia de ingresos y recursos financieros existen, la mayoría de las familias afrontan una carga financiera a causa de la condicion de su niño. Muchas veces esta carga es ocasionada por la compra de equipo para su niño. Considerando que una silla eléctrica de ruedas puede costar $15,000 y una computadora con periféricos $5,000, esto es fácilmente posible. Los costos de reparación y conservación de equipo raramente son reembursados por el seguro o Medicaid puede ser también desastrosos económicamente. Reemplazar algo tan común como la cubierta del asiento de la silla de ruedas puede ser un desembolso de $65 a la familia.

Los recursos emocionales y de apoyo disponibles a las familias varían a través del estado. Algunas familias reciben ayuda con responsabilidades cuidadoras dado por miembros de la familia y amigos. Algunos tienen una red de amigos, otros padres, y profesionales para ayudarlos cuando se presenta un desafío, pero ellos están en una minoría diferente. Otras familias reciben cuidado o servicios de enfermería de fuentes externas. Muchas familias batallan con el desafío de crear un niño quien está sordo y ciego por ellos solos.

Conocimiento de organizaciones que pueden proveer ayuda y apoyo es severamente escaso entre los padres del censo. La mayoría de los padres nunca han oído (ni recibido ayuda) de la Asociación Nacional de Familias de Sordos y Ciegos (NFADB), El Proyecto de Doble Impedimiento Sensorial de Kansas (KDSIP), "Task Force" de Sordo y Ciego de Kansas, o la Biblioteca para Sordos y Ciegos de Kansas.

En gran parte a iglesias locales o servicios de grupos como el Kiwanis y el club de Leones parecen ser las fuentes primarias a los cuales familias tornan por asistencia. Generalmente hablando, el apoyo suministrado por escuelas es limitado o no existe. De cualquier fuente ayuda es recibida, sin embargo, es generalmente por solo una vez (ej., para comprar una pieza de equipo). Lo que aparece ser poca ayuda continua en la que familias pueden confiar.

A pesar de tal apoyo limitado, muchas familias sacan fortaleza por su fé, de creer en lo que vale su niño, y por el gran cariño por su niño.

Lo qué los padres quieren y necesitan para ellos

Tres importantes necesidades surgieron en esta encuesta para los padres: el acceso a la información práctica sobre temas de sordos y ciegos, la facilidad para hablar con los padres que tienen niños con necesidades de salud similares, y personal mejor entrenado para trabajar con sus niños.

1. Acceso a información

Cuando los padres se preguntarón cual sería la mejor manera de obtener información sobre temas sordo y ciego, su abrumadora respuesta fue un boletín.[1] Frustrados con acomodar las demandas de trabajo y del hogar con las necesidades especiales de su niño, los padres expresaron su deseo de información que sea rápida para digerir, fácil comprender, y portable. Específicamente, los padres dijeron que ellos buscan información de como ayudar sus niños a comunicarse, llegar a ser miembros valorados de sus escuelas y comunidades, y eventualmente, para vivir y trabajar independientemente. Los padres con niños que se acercan al fin de escuela superiora expresaron su deseo por información sobre la educación post secundaria, programas de adiestramiento y organizaciones que les enseñan la vida diaria y habilidades vocacionales, y oportunidades de trabajo.

Como un corolario a este deseo por información, los padres expresaron fuerte oposición para obtener información mediante cursillos o conferencias.[2] Aun cuando los cursillos tuvieran en un lugar cerca y el cuidado de niños se proveyera, los padres dijeron que ellos tenián demasiadas otras responsabilidades para usar su tiempo en un cursillo.

2. La capacidad para hablar con otros padres

Los padres también expresaron gran deseo de hablar con padres quien tienen niños con similares capacidades o necesidades de salud. Los medios abrumadores por los que ellos quieren conducir estas conversaciones es por teléfono no en una reunión. Como un corolario a este deseo, muchos padres expresaron el interés en una red de padre-a-padre para familias de niños quien son sordos y ciegos.

3. Personal de apoyo mejor entrenado

Finalmente, los padres quieren que la gente involucrada en la educación y el cuidado de su niño este mejor entrenada. Para el niño con necesidades especiales de salud, personal con bajo entrenamiento posa un peligro potencial. Entrenando personal a identificar con exactitud la actividad de un ataque y

1 Esta opción se seleccionó de las siguientes opciones o posibilidades: boletínes de información, periódicos locales, cassettes, videos, "e-mail", "web sites", y conferencias o reuniones regionales.

2 Para padres familiar con Fines de Semana de Enriquecimiento de Familia—un retiro educativo organizado y patrocinado por Familias Unidas—esta oposición para asistir a cursillos fué también cierta. Los padres quien habían asistido anteriormente a estos eventos dijeron que ellos ya no asistieron más porque las actividades fueron dirigidas más hacia familias cuyos niños tenian diferentes necesidades. Preocupaciones sobre la capacidad de asistentes voluntarios de ser capaces de entender y comunicarse con niños quien son sordo y ciego también contribuyeron a su decisión de no asistir.

saber que hacer cuando un niño lo tiene es una necesidad importante.

En particular, a los padres les gustarían que el personal de apoyo reciba entrenamiento en como establecer amistades de compañeros, inclusión, colaboración de equipo, comunicación, y dirección de comportamiento. De particular interés a los padres de niños con problemas de salud es que los paraeducadores y cuidadores sepan como mantener la salud del niño y su bienestar. Además, los padres dijeron que ayudantes del personal o suplentes necesitan ser entrenados. Cuando un paraeducador está enfermo, los estudiantes son forzados a permanecer en casa algunas veces porque no hay ningún otro que sepa como cuidar de los niños.

Otros intereses sobre las habilidades del personal incluyen:

- para niños que usan lenguaje de signos, tener personal en la escuela que sea capaz de signar al mismo nivel que el niño (y con el mismo tipo de señal de lengua);
- para niños que usan ventiladores, tener más proveedores de salud pública entrenados en el uso de ventiladores;
- para niños que usan sillas de ruedas eléctricas, tener más instructores de Movilidad y Orientación experimentados en trabajar con la movilidad eléctrica, y
- para adolescentes que estan transfiriendo al mundo de trabajo, tener entrenadores de trabajo bien preparados.

"Frustrado de batallar con las demandas de trabajo y casa con las necesidades especiales de su niño, los padres expresaron un deseo para información que sea rápida para digerir, fácil de entender, y portable."

Lo qué los padres quieren para sus niños

Durante la encuesta, los padres también mencionaron tres deseos importantes para sus niños: aprender un sistema de comunicación funcional, a tener acceso a más tecnología, y tener acceso a más significativas oportunidades de empleo.

1. Aprender a como comunicarse

Padres se dan cuenta de que la comunicación, cualquiera que sea el estilo o nivel de capacidad, es esencial para la calidad de vida de sus niños. Muchos padres naturalmente perciben que lo qué interpretan frecuentemente como mal comportamiento de parte de su niño es simplemente el intento del niño de comunicarse cuando ningún otro medio es disponible. Los padres quieren encontrar maneras más apropiadas socialmente para que su niño se comunique. Además, ellos ven la abilidad de comunicarse como un punto importante para su seguridad aunque frecuentemente se descuida. Los niños necesitan poder expresarse aún que alguien los haya amenazado o lastimado, y aún cuando alguien los halla hecho sentir incómodos.

2. A tener acceso a más tecnología

En muchos casos, los niños necesitan tecnología y equipo adaptable a fin de comunicarse, aprender, acceso a aprender, hacer un trabajo, o competir académicamente con compañeros no-incapacitados. Tener gente cualificada que comprenda las diversas necesidades de los niños quien son sordo y ciego y que tienen la pericia seleccionar tecnología y equipo para satisfacer esas necesidades es esencial. Así como es importante tener profesores que sepan como usar la tecnología o equipo una vez que está disponible.

Los padres quieren que sus niños usen tecnología y que tengan un mayor acceso a esta tanto en la escuela como en el hogar. Usando tecnología solamente en la escuela no prepara al estudiante para su uso en el hogar o en la comunidad. Los padres frecuentemente no pueden invertir en doble equipo o tecnología para usarlo en el hogar. Así, que a ellos como a sus niños quisieron poder transportar la tecnología entre el hogar y la escuela, o tener un programa de préstamo sin interés que les permitiera comprar el equipo necesario. Y, ellos quieren que el equipo y tecnología que los estudiantes usan en la escuela que los siga en la vida real.

3. A tener acceso a oportunidades más significativas de trabajo

Los padres se preguntan lo qué sus niños harán una vez que ellos se gradúen. ¿Habrá trabajos para ellos, o pasarán días aislados? ¿Y qué sera de sus niños una vez ellos mueren? ¿Quien cuidará de ellos? Así, que el tercer deseo que los padres tienen para sus niños es el de que ellos adquieran las habilidades que ellos necesitan para funcionar como adultos, y poner más énfasis en el desarrollo de trabajos mas significativos para estudiantes quien son sordos y ciegos.

Para los padres de niños más jovenes, hacer planes para cuando su niño llegue a la edad adulta es un concepto difícil de considerar. Muchos estan tan abstraidos con la lucha del momento que sujetos como "arreglos para el futuro de sus hijos" y "empleo" son tan remotos como la luna. Muchos padres no se dan cuenta de que necesitan buscar custodia para su hijo cuando llegue a los 18 años de edad. Y, muchos no saben que los muchachos necesitan registrarse para el servicio militar (draft) aún cuando ellos tengan incapacidad.

Lo qué nosotros podemos hacer para ayudar

Aunque la situación puede parecer penosa, nosotros podemos hacer mucho para mejórarla. Algunas familias estan bien y sus niños estan recibiendo los servicios que ellos necesitan. Esto parece suceder más con niños preescolares y niños más chicos, que quizás cuando los niños pasen a la escuela elemental, mucho del trabajo básico será puesto para una experiencia de escuela más productiva.

Generalmente, las familias que obtienen servicios lo hacen porque ellos usan la red (network) y negocian. Desafortunadamente, no todos los padres tienen las habilidades de un abogado, activista, negociador, y político científico. Los niños deberían poder conseguir los servicios que necesitan aún cuando su madre no sea Sandra Day O'Connor. La carga no debe caer sobre los padres. Padres y profesionales necesitan trabajar juntos para ayudar a cada niño en Kansas a obtener la educación que ellos merecen.

Entre maneras específicas que padres y profesionales pueden trabajar juntos incluyen:

- estableciendo un grupo interado de padre/familia para proveer guía continua sobre los tipos de servicios necesitados en el estado;
- explorando el uso de la "Internet" como medio de acceso de recursos no solo en el estado pero a través de la nación;
- explorando la mayor colaboración con agencias existentes para padres y familias, y
- explorando el establecimiento de una "website" como medio de comunicación de padres de uno con otro.

¿A donde vamos de aquí?

En respuesta directa a las necesidades en la encasta discutida en este informe, tres cambios positivos han ocurrido ya.

Primero, un directorio de teléfonos con nombres de padres incluida por concentimiento ha sido preparado y diseminado mediante los esfuerzos coordinados de numerosas agencias.

Segundo, en un esfuerzo para proveer a padres a través de el estado con el acceso a la información práctica, un boletín informativo para los padres ha sido establecido. El contenido de este boletín informativo fué ideado, escrito, y revisado por padres de niños quien son sordos y ciegos. El boletín informativo se publica dos veces al año en Inglés y en Español.

Tercero, varios equipos de transición se han establecido para facilitar la transición de estudiantes quien son sordos y ciegos a un empleo significativo, vivir independientemente, y oportunidades de recreación dentro de sus comunidades domésticas. La fuerza impulsora trás las actividades de equipos son las necesidades y las preferencias individuales del estudiante. Por ejemplo, a un estudiante se le ha ofrecido empleo de tiempo completo (con beneficios) tras su graduación de la escuela superior. Otro estudiante regresa a su comunidad doméstica para asistir la escuela de su elección. Y otro estudiante ha aumentado sus actividades sociales mediante su relación con el YMCA local, donde él ha desarrollado muchas amistades sinceras y naturales.

Si bien estos cambios pueden aparecer pequeños, ellos han mejorado mucho las vidas de niños y familias en Kansas, y han llegado a ser puntos de lanzamiento para conecciones adicionales.

Finalmente, la cosa más importante que nosotros podemos hacer es creer en el mérito de niños quien son sordos y ciegos. Nosotros debemos continuar enseñando educadores, administradores, doctores, enfermeros, trabajadores sociales, conductores de autobus, vecinos, y políticos que estos niños son importantes y su educación es importante. La verdadera nota de esperanza, oida una y otra vez de como padres hablan de sus niños, es el amor profundo y obligaciones que estas familias sienten hacia sus niños. Es su fortaleza. Junto, ese amor es nuestra esperanza—para el futuro de niños quien son sordo y ciego en Kansas. ❧